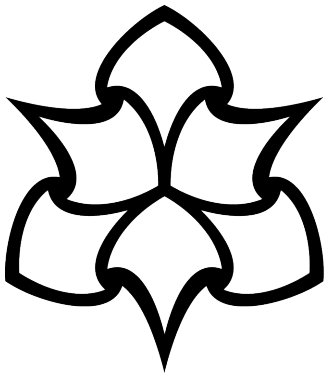

The challenges and facilitators to successful translation and adaptation of written self-report psychological measures into sign languages: a systematic review

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Abstract

Deaf people are known to have significantly poorer reading comprehension skills when compared to their hearing counterparts. This poses significant threats to text-based psychological assessments. The plethora of text-based self-report measures available provides ample opportunity to translate/adapt existing tools from text to sign language. This paper systematically reviewed the challenges and facilitators faced in previous translations/adaptations with the view to inform recommendations for future practice. This paper reports the results of a PRISMA informed systematic review of 30 studies that had translated or discussed the translation of a written self-report measure into sign language following screening against inclusion/exclusion criteria. A systematic search (powered by EbscoHost Research Database and using search terms and Boolean operators), was performed in AMED, Cinahl, Medline, APA PsycInfo and APA PsycArticles. The Quality Assessment with Diverse Studies tool was used for quality appraisal of the included papers. Challenges/facilitators to effective translation/adaptation were grouped under linguistic, procedural and cultural. Examples of specific linguistic, procedural and cultural challenges and facilitators are discussed in the context of previous research and study limitations. Translating/adapting text-based self-report measures to sign language is a linguistically and procedurally demanding endeavour that requires a deep bicultural/bilingual understanding of both deaf and hearing communities. The present results and recommendations can help researchers develop suitably accessible translated/adapted self-report psychological measures and this can have significant implications on healthcare service planning and delivery.

Keywords: deaf; self-report measure, adaptation, translation, sign language, systematic review

Public significance statement

Self-report questionnaires in text format are not always accessible by all deaf adults and pose a threat to the reliability of test scores and the validity of the test score

interpretations. When translating and culturally adapting written measures to sign language researchers need to address linguistic and procedural challenges and accommodate the cultural differences between the deaf and hearing populations.

Cultural identification, language preference (sign vs spoken), parental hearing status (deaf vs hearing), degree of deafness, technological aid used, and type of schooling are some of the key characteristics that constitute deaf ontology. As a result, there is considerable diversity in terms of ways by which deaf people identify themselves, including deaf, Deaf, hard of hearing or cochlear implant users[1]. The present review focuses on the communicative needs of those people who irrespective of how they self-identify use sign language as their primary/preferred method of communication and who, therefore, would prefer sign over text whilst completing self-reported questionnaires. These people have historically been experiencing inequalities in accessing appropriate education (Skyer, 2020), healthcare or employment (Grote & Izagaren, 2020) or simply general information (du Feu & Chovaz, 2014). Evidence suggests that, overall, deaf people experience a greater number of mental health problems (du Feu & Chovaz, 2014; Horne & Pennington, 2010) and have a poorer quality of life relative to the hearing population (Cieśla et al., 2016). Research has consistently demonstrated that the incidence of mental health problems in deaf people, such as depression, is higher than that of the hearing population (Sign Health, 2014) and that certain characteristics of specific severe and enduring mental health problems, such as schizophrenia, manifest themselves differently in deaf people than in hearing people (Chatzidamianos et al., 2018).

Despite this increased incidence or differently manifested mental health experiences, deaf people are historically confronted with significant struggles when trying to access mainstream mental health services owing to the multitude of communication barriers that

[1] By convention Deaf (with a capital ‘D’ vs deaf with lower case ‘d’) often refers to those deaf people who identify themselves as belonging to the Deaf community and use their national (or regional variant) sign language as their primary method of communication (Levine, 2014). As the purpose of this paper is beyond the cultural identification of deaf people, we use the term deaf inclusively throughout to refer to those who self-identify as deaf, Deaf, hard of hearing or cochlear implant users and have sign language as their preferred method of communication. For information specifically on the debate between Deaf vs deaf cf. Friedner and Kusters (2020).

they face (Cabral et al., 2013). Mainstream healthcare professionals, who most likely are not proficient in sign language, tend to misunderstand the specific needs of deaf people during consultations, with deaf individuals feeling that they have received inadequate support from their doctor (Berry & Stewart, 2006; Lesch et al., 2019; Panzer et al., 2020). This, in turn, could ultimately risk patient safety. For instance, one in four deaf patients have been prescribed medication without a comprehensive overview of the drug and/or reported falling seriously ill by consuming a medicine intended for external application (Reeves & Kokoruwe, 2005). These shortcomings within the healthcare setting often exacerbate feelings of loneliness and misunderstanding which, in turn, contribute to poor mental health outcomes for the deaf population (Movallali et al., 2018). Importantly, the context within which these misunderstandings occur is one whereby deaf people experience a lack of understanding of psychotherapy (Neves et al., 2020) or do not trust health professionals (Pereira & Fortes, 2010) and, therefore, often report low satisfaction from mainstream services (Iezzoni et al., 2003).

In their discussion of how deaf people's psychological needs could be met by hearing clinicians who are experts on deafness, Glickman and Gulati (2003) stressed the importance of 'cross-cultural legitimacy'; a term originally proposed by Pollard, (1996: 393) to describe those hearing clinicians who can provide services in sign language and who have earned a deep understanding of the issues faced by the deaf community through consistent and cross-cultural interaction with deaf people. Indeed, deaf specialist services appear to result in better use of preventive services (McKee et al., 2011).

There are many communication barriers that deaf people face when consulting with healthcare professionals. For instance, many deaf signers find access to health provision difficult due to deficient communication strategies or challenges even when sign language interpretation services are provided (Chatzidamianos et al., 2019). Such barriers are not just

found in dialogic-based environments or interpreter-mediated consultations where healthcare professionals often misunderstand the specific needs of a deaf person, but also in communicative interchanges that require the use of written text. For instance, except for image-based, neuropsychological or interview-based assessments, most self-report psychometric measures are constructed in a written format, presenting a significant barrier to completion and subsequently impacting the identification and treatment of pertinent (mental) health conditions. This is because research has consistently demonstrated that deaf individuals often possess lower levels of both health literacy (Pollard & Barnett, 2009) and reading ability more widely compared to their hearing counterparts (Qi & Mitchell, 2012), thus posing the risk that written questionnaires do not accurately measure what they have been designed to assess. As a result, deaf people are frequently under-represented in (mental) health research, partly, owing to the paucity of standardized measures accessible to them, which, for instance, hinders the completion of epidemiological research to identify accurate data on the prevalence of mental health issues within the deaf population or the assessment of their needs (Chatzidamianos, 2015).

Self-report psychometric measures are frequently translated from one written language to another. The effective translation of such measures is critical in ensuring that the needs of deaf people are consistently met and that any observed differences of scores are not the result of a poorly translated measure (Maneesriwongul & Dixon, 2004). Whilst constructing a new self-report measure directly in sign language might be the most appropriate approach to ensure that the measure is sensitive to the target population, it is usually a laborious and expensive process (Hall et al., 2018). Instead, by drawing upon the multitude of measures readily available and translating and culturally adapting them, we would be in a better position to create rigorous and consistent measurements in the target language. The remaining sections highlight the difficulties associated with doing so.

Translating a self-report written measure into sign language is not without its challenges. Haug and Mann (2008) elucidate the difference between adaptation and translation in this regard. For example, adaptation captures the entirety of the process, whereby not only is the meaning of each item transmuted into the target language but the cultural differences between both are also captured satisfactorily. The linguistic heterogeneity of the deaf population (in itself a product of early language experiences/deprivation, schooling environment, the hearing status of immediate family members), the deaf specific cultural parameters and the specific linguistic nuances of sign language complicate the adaptation process considerably (Morere, 2013). The different communicative modalities between speech and sign then complicate the process further (Quer & Steinbach, 2019). Transliterating text into sign language, therefore, would not necessarily convey the intended meaning or capture the nuances of the Deaf culture effectively, and would almost certainly result in an incomprehensible sign language version. The primary aim of adaptation, in this respect, is to achieve cross-cultural and conceptual equivalence, not merely linguistic similarity. This is where adaptation can pose a variety of challenges that potentially risk the production of a measure in the target language with unacceptable validity of the test score interpretations.

A variety of methods to adapt written self-report measures have been posited as research has evolved. Since Brislin's (1970) early work, more recent works are settling on the forward/backward translation method as the most rigorous and accurate (Andrade et al., 2018) which also complies with relevant guidelines specifically for assessments of health outcomes (Acquadro et al., 2012). In this approach, either an individual or a translation team is tasked with an initial translation of the source material, known as the forward translation. The initial translations are then reviewed by an expert panel to ascertain whether they have captured the intended meaning of the original instrument. Once these translations are

finalized, an independent back translation individual or team, without prior knowledge of the original instrument, translates the sign language versions back into the original language. The back-translation is compared to the original measure to corroborate whether the translation has been successful in retaining its intended meaning. This is often supplemented by cognitive interviews that are used to assess the acceptability of the newly translated scale by the target population and are conducted with target users on the final draft of the translated/adapted scale. Drennan (2003) argues that cognitive interviews are an efficient method that is frequently been used across health care research to pre-test questionnaires in the prototyping phase and to ensure high response rates during field testing. Field testing ensues to establish the internal consistency and reliability of the test scores of the new translated instrument. Cognitive interviews, also referred to as structured interviews or think-aloud protocols with selected test takers or cognitive labs, are also been proposed by the Standards for Educational and Psychological Testing (American Educational Research Association et al., 2014: p. 82; *Standards* thereafter) as a means to "identify irrelevant barriers to responding correctly that might limit the accessibility of the test content' and to "evidence that the cognitive processes being followed by those taking the assessment are consistent with the construct to be measured" (cf. Standard 4.0, *ibidem*, p. 87).

Whilst the adaptation process is often described at length in each respective study, there has been relatively little discussion concerning the specific challenges faced during the adaptation process from text to sign. A recent systematic review within the translation domain, however, proposed that forward-backwards translation is the best practice (Andrade et al., 2018). However, the review focused specifically on the methodologies used for the translation of health research instruments from text to sign by comparing different processes of different constellations of the translation teams: individualized translation processes; group translation; translations with adjustments by a monolingual and bilingual group; and mixed

translations. Understanding and anticipating the challenges to successful translation would facilitate efficient translation from text to sign and support increased efforts to adapt more clinical measures from text into sign language, thus improving access for what is, in effect, an often-underserved populace. Generating adaptation recommendations, based upon the existing literature, would contribute toward best practice in translation research. Whilst acknowledging that translation and adaptation are conceptually different (Herdman et al., 1997), we use the two terms interchangeably for simplicity purposes.

Present study

The present paper aimed to review the specific challenges and facilitators faced in previous efforts with the view to advance recommendations when translating/adapting written self-report measures into sign language(s). To gather all evidence and synthesize it effectively, a systematic review approach was selected because it allows the examination of the existing literature methodically and rigorously (Paul & Leibovici, 2014). The research question was: What specific challenges and facilitators are encountered when translating/adapting written self-report measures into sign language, and what steps are recommended to facilitate the process?

Method

This being a systematic literature review of peer-reviewed articles it did not require institutional ethics review. This review was conducted in line with the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) statement 2020 (Page et al., 2020). The PRISMA statement includes a 27-item checklist that describes the actions and decisions recommended to ensure total transparency throughout the review process.

Inclusion criteria

Studies were included in the review if they: (a) described the translation/adaptation of a written self-report measure into a sign language, (b) were an original peer-reviewed journal article.

Exclusion criteria

Articles were excluded if they: (a) belonged to grey literature (e.g. blogs,) (b) described the translation of a different format of text other than self-report psychometric measures (e.g. interview) (c) were systematic literature reviews (d) adapted a self-report measure from one sign language to another [e.g. American Sign Language (ASL) to British Sign Language (BSL)] (e) produced a new self-report measure in sign language, without translation, within the study.

Information Sources and Search strategy

Search terms were carefully selected to ensure that all relevant literature was captured. The Boolean operators "AND" and "OR" were used to broaden the search and include various synonyms of keywords. Asterisks (*) were used to truncate keywords and include all variations of each word rather than increasing the search string. For example, the terms "translate" and "translation" are shortened to 'translat*'. The search terms were as follows:

1. translat* OR adapt* OR accom* OR guid*
2. questionnaire* OR scale* OR measure*
3. "sign language"

Line one was designed to include all words that allude to the translation, or transformation, of one measure to another. We decided to include several synonyms on this line to cast a wider search net. The second line included keywords that would identify all papers discussing self-report questionnaires and, hopefully, omit the translation of other forms of written text such as a diagnostic interview or prose text. To avoid limiting results on a specific sign language and develop a synthesis from international data, the third line used the search term "sign language" (as opposed, for instance, to British Sign Language). Search terms were entered into EBSCO Research Databases with the following databases included: AMED, Cinahl, Medline, APA PsycInfo and APA PsycArticles. Each search was conducted

three times; one search by title, one by abstract and one by keywords. The PRISMA flowchart (see Figure 1) illustrates how the research team identified records that were considered relevant to the research question.

Selection Process

Initial search results were exported from EBSCO Research Databases into Covidence (Veritas Health Innovation, n.d.); an online-based systematic review manager that facilitated the organization and screening of records. Two of the papers' authors were included as reviewers in Covidence to conduct the initial screening. All records were screened by title and abstract by two reviewers independently. There were 98 articles that both reviewers agreed on including in the review, 103 where both reviewers agreed on excluding, 9 where the first reviewer excluded and the second included. Finally, there were 17 articles that the first reviewer included and the second did not. Interrater reliability analysis on these data showed that there was a substantial agreement between the two reviewers (88.5%) as indicated by the Cohen's Kappa coefficient $k = 0.77$, $p < 0.001$ (Landis & Koch, 1977). After the two reviewers completed their initial screening independently, they met to resolve any conflicts prior to moving records into the full-text review stage. This was conducted to reduce reviewer bias and encourage open discussion between the reviewers.

The full-text review stage was undertaken by one reviewer where papers were assessed for their eligibility based upon the criteria established by all authors before the search commencing. Each paper was accessed in its entirety via the university's library (where possible). Study authors were also contacted directly either via email or ResearchGate. Each article included in the full-text review stage was scrutinized for potentially relevant papers in its cited references (i.e. backward-searching). Similarly, each article was forward searched to identify papers that had cited it (i.e. forward-searching). All articles that were thought to be potentially useful were uploaded into Covidence for further

scrutiny. Papers that met all inclusion criteria were then moved into the quality appraisal phase.

Quality Appraisal

The tool used to perform the quality appraisal was the Quality Assessment with Diverse Studies (QuADS) (Harrison et al., 2021), chosen for its substantial inter-rater reliability (k=0.66) (Landis & Koch, 1977), and face and content validity for application in systematic reviews with mixed, or multi-methods health services research (Harrison et al., 2021). The tool is an updated and reduced in length revised version of the Quality Assessment Tool for Scales of Diverse Designs (QATSDD) (Sirriyeh et al., 2012). It consists of 13 criteria that are scored on a 4-anchors Likert-type scale that ranges from 0 to 3. The appraisal does not result in a final total score for each paper. Instead, it follows a 7-step process (described in the tool's instruction manual available on request by the original authors). To enhance the rigour and reliability of the scoring, using the QuADS, a sample of 15 randomly selected records were first reviewed independently by two reviewers, each blind to the scoring of the other. For those 15 papers, each reviewer produced a total of 195 scores (15 papers x 13 criteria per paper). An inter-rater analysis of these scores showed that there was a substantial agreement (81.44%) between the two reviewers as indicated by Cohen's kappa coefficient $k = 0.728$, $p < 0.001$ (Landis & Koch, 1977). The remaining 15 papers were only reviewed by one of the reviewers. Further, in line with our over inclusive strategy, we also reviewed 3 opinion papers that met the inclusion criteria. As the QuADS is not suitable for opinion papers, these were appraised using the Joanna Briggs Institute Critical Appraisal Checklist for Text and Opinion Papers (McArthur et al., 2015), which structures the appraisal of each paper upon 6 closed questions (possible answers: Yes, No, Unclear or Not/Applicable) (see Table 1).

[insert Table 1 here]

Data extraction and Coding

A data extraction form was developed. This was produced iteratively by all members of the research team. The review team consisted of two clinically trained academic psychologists (one with a background in experimental psycholinguistics and one with a background in socio-clinical psychology), a linguist, and a senior health researcher. We believe that the plurality of backgrounds of the team enhanced the review process and outcomes as its interdisciplinary nature allowed for multiple evidence-based ideas and viewpoints to be incorporated. Each member of the team contributed to the final design of the extraction form. The development of the form was based on the information reviewed in the context of the initial screening and the quality appraisal and the familiarity of the reviewers with the literature on deafness. The form was then piloted with 5 randomly selected studies to test its efficacy. Key data collection points were agreed upon prior to data extraction commencing. These collection points were informed by the review question and its a priori focus on the challenges and the facilitators. Amongst the data points collected was the design of the translation team. Understanding how research teams have previously approached the translation team design, the specific experience of the translation team members and their overall involvement with the signing community were all deemed to be pertinent to the research question.

Further, to accurately capture the challenges and facilitators to efficient translation/adaptation of text to sign in the included papers, the challenges and the facilitators were grouped under three broad categories: linguistic, procedural and cultural. These were designed to categorize elements of the multifaceted adaptation process previously described. A linguistic challenge/facilitator was conceptualized as a language-related process that blocked/enabled the accurate translation/adaptation of a concept between the two languages. A procedural challenge/facilitator was understood as a process followed that hindered/facilitated the logistical or practical element of translation, such as uses of

technology. Cultural challenges/facilitators captured those processes that were deemed (in)sensitive and/or (un)responsive to issues specifically relevant to the Deaf culture, deaf attitudes or communication amongst signers.

The team also decided that identifying recommendations for future action, along with any relevant technology mentioned, would contribute toward a best practice guide for translation/adaptation. Therefore, any framework or previous translation efforts cited as underpinning the research outputs' approach to translation was also captured. Challenges and facilitator were coded in line with thematic coding in content analysis, whereby certain segments of text are identified, recorded and organised into categories, thereby creating a taxonomy or category scheme with different categories and subcategories (Attride-Stirling, 2001; Saldana, 2013). One of the reviewers read the results section of each paper line by line and coded them into the different categories (i.e. challenges or facilitators) and subcategories (i.e. procedural, linguistic, cultural).

Results

A total of 228 studies were identified through database searches, with manual reference searching (backward/forward-searching) producing a total of 40 additional studies. Duplicates were subsequently removed (N=55). A total of 213 records were screened by title and abstract with 147 studies excluded at this stage. Sixty-six articles were subjected to full-text eligibility against the review's inclusion/exclusion criteria. Thirty-six studies were excluded for a variety of reasons (see Figure 1). Thirty studies were included for final data extraction (see Figure 1). Facilitators and challenges were subsequently extracted and inputted into the final data extraction sheet. For a detailed description of linguistic, procedural and cultural challenges and facilitators see Table 2.

[insert Figure 1 here]

Study characteristics

Out of the 30 studies, most studies were based in the USA, translating written English into ASL (n = 13). This was followed by studies conducted in the UK, translating from written English into BSL (n = 7). Three studies originated in Brazil and translated Portuguese into Libras and 2 were based in Australia, translating written English into Australian Sign Language. There was also a single study conducted in each of the following countries: Israel, Spain, Sweden, Norway and Austria, each of which translated from the country's national written language to its national sign language.

Most of the reviewed studies utilized a forward-backwards translation approach (n = 27); the rest (n=3) (Bisol et al., 2008; Brauer, 1992; McKee et al., 2015) either did not explicitly state whether the forward-backwards approach was employed or referred only to the composition of the translation team. A closer look at the methodological approach to adaptation (see Table 2) showed that those authors[2] (n=13) who applied an *elaborate* forward/backward approach that also consisted of focus groups or review panels/judges/committees with members of varied expertise and language backgrounds were in a better position to pre-empty potential pitfalls and report more nuanced challenges and facilitators of the translation/adaptation process compared to those[3] (n=14) who reported following a forward/backward approach only or reported the translation of a scale from its written version to a sign language one (n=1) (Bisol et al., 2008), or did not specifically report the exact methodological approach to adaptation (n=2) (Brauer, 1992; McKee et al., 2015)[4]. Importantly, however, no study incorporated a cognitive interview component at the

[2] Aanondsen et al., 2019; Andrade et al., 2019; Berke et al., 2019; Chaveiro et al., 2013; Jones et al., 2006; Montoya et al., 2004; Moore et al., 2013; Pardo-Guijarro et al., 2013; Roberts et al., 2015; Rogers et al., 2013a, 2013b, 2014; Samady et al., 2008.

[3] Berman et al., 2000; Brauer, 1993; Cornes et al., 2006; Cornes and Brown, 2012; Crowe, 2002; Fellinger et al., 2005; Glickman and Carey, 1993; Graybill et al., 2010; Levinger and Ronen, 2008; Rogers et al., 2016, 2018; Smith and Samar, 2016; Tweney and Hoemann, 1973; Wahlqvist et al., 2016.

[4] For challenges and facilitators to translation/adaptation, Rogers et al. (2018) signposts readers to Rogers et al. (2013b).

prototyping phase of the translation/adaptation. A summary of the characteristics of the included studies can be found in the supplemental material.

Challenges and Facilitators

Overall, there were 79 challenges (49 linguistic, 12 procedural, 18 cultural) and 75 facilitators (22 linguistic, 30 procedural and 23 cultural), with some repetition across the studies.

Linguistic challenges

The most common linguistic challenge involved the need to replace specific written words that do not convey the same meaning in sign language with others that are conceptually/semantically similar. This could include terms with no sign equivalent (e.g. ‘quality of life’), problematic concepts when translated (e.g. time or duration), or idiomatic expressions (e.g. ‘feeling on edge’). Four authors identified the problematic use of personal pronouns. Three authors noted that the use of Likert scales posed additional linguistic challenges because severity anchors (e.g. true, certainly true, somewhat true, etc.) are typically conveyed in sign language using the appropriate/relevant facial expression. Indeed, what would be perceived as paralinguistic information in verbal communication (e.g. lowering eyebrows to signify specific emotions, concentration, disapproval or anger) could be a part of grammar such as a punctuation mark in sign language (e.g. a question mark).

Procedural challenges

Overall, there were 12 procedural challenges identified, with some being reported across studies. The most common procedural challenge related to technology and formatting issues. Certain issues appeared less frequently; for example, the recruitment of participants, time restrictions and editing and the use of free-text response. Examples of procedural challenges included: reiterating instructions for the measure before each item to retain the validity of the test score interpretation, signs that move perpendicular to the camera being hard to distinguish, and difficulties editing with certain technologies such as videotapes.

Cultural challenges

There were 18 cultural challenges, overall, with some being reported across studies. These challenges did not prevent successful translations. The authors of the reviewed papers highlighted them as issues that required attention. Examples of cultural challenges included: non-applicable items within measures that are not relevant for the deaf community (such as items relating to hearing), and the translation team potentially not reflecting the larger deaf community. Accurately considering and accommodating deaf peoples' experiences into the translation process was the most commonly reported challenge. Varying levels of language knowledge was the second most common challenge. Ensuring the involvement of members of the deaf community was also considered a challenge to a successful translation. One author noted that, culturally, deaf people are not accustomed to completing surveys which posed a significant barrier more generally with completing self-report measures. One instance of signer-related issues was also reported where the notoriety of the signer within the deaf community was suggested as impeding completion.

Linguistic Facilitators

The most common linguistic facilitator was the importance of the translated/adapted version to avoid a mere linguistic transliteration of the original text but to focus on linguistic equivalences. One author suggested that for difficult category words, translation teams should contact the original authors of the scale to seek clarity on the intended meaning of the word. Other authors suggested that translation/adaptation efforts would be more effective when the team consists of native or near-native signers. This is, as other authors pointed out, because such signers would be in a position to capitalise on the sign language syntactic features such as referential indicators, facial expressions and topicalization with a range of inflectional endings to overcome complex written concepts. A recurrent linguistic facilitator included the presentation of a captioned video that presents both the signer communicating the test items and the captions of what they say and not of what the original text version of the measure

stated. Another reoccurring linguistic facilitator involved a (re)consideration of the use of pronouns from first person singular/plural to the second person equivalent as a means to ensure that respondents understand that items/questions are addressed to them and not the signer who appears on the screen. Two authors removed colloquialisms from the signed version and opted for a simple sentence structure without multiple clauses. One author emphasised the importance of the translated version to be psychologically equivalent specifically in relation to sensitive items.

Procedural Facilitators

The most frequently occurring procedural facilitators involved the need for clear instructions and procedures in the development phase and using internet hosting for the end product. Some authors discussed specific technical facilitators (e.g. use of a second monitor, empty text fields and 'topic box' fields) and the importance of providing a video replay facility. Facilitators that occurred once included the use of fewer multiple-choice as an option of responses, the addition of a video dictionary for difficult terms, and extensive pretesting to improve face validity. One author proposed that a 10-second interval between items would allow respondents to answer without having to replay each item. Finally, one author stressed the importance of signers wearing dark clothes and stand against a solid background so that the signing is clearer.

Cultural Facilitators

Finally, the cultural facilitator that featured the most frequently was the pre-existing knowledge/awareness of the Deaf culture and experience in working within the Deaf community. Diversity was a key construct across many cultural facilitators. Specifically, the diverse constitution of the translation team was perceived to be integral to effective translation/adaptation. Also, in recognition of the diverse nature of the Deaf community, authors perceived switching signers in the video version of the scale to facilitate the development of a scale that is sensitive to issues such as gender, age, educational background

and language ability. Two authors described that focus groups at the development phase helped with ensuring that the end product was culturally equivalent.

A comprehensive list of all challenges and facilitators can be found in Table 2.

[insert Table 2 here]

Discussion

Ensuring access to appropriate measurement tools for the deaf population worldwide is of critical importance, owing to the specific health inequalities this population faces. Despite this stark need, routine translation of measures developed for use with the deaf population is not occurring in a concerted, regulated or urgent manner. This leaves a substantive portion of deaf people bereft of equal access to (mental) health services pertinent to maintaining and fostering positive mental wellbeing (Chatzidamianos & Fletcher, 2019). This review aimed to identify the specific challenges and facilitators to an efficient and accurate translation/adaptation of self-report measures from text to sign. Understanding the nuances of the translation/adaptation process that potentially impact future efforts would encourage more frequent attempts and arguably, improve accessibility for a typically underserved populace. The review identified and organised a plethora of potential issues faced.

Linguistic Challenges and Facilitators

The results demonstrated that the most commonly reported challenges and facilitators were linguistic. Of these, attempting to equate a word or phrase from its written format into sign language was often found to be the most difficult. Rather than a straightforward exact transliteration, it is paramount that the meaning of the word within that culture is effectively conveyed. For example, the term “God” when written in English can refer to any number of religious figures across religions. However, “God” in ASL is signed differently dependent on the religion in question (Samady et al., 2008). Terms such as this, with various signs in sign language, can be challenging to translate for a range of deaf audiences without risking

alienating or even offending specific subgroups within the deaf population. Consultations with members of the deaf community aiming to identify an equivalent term that is inclusive and can capture the intended meaning periphrastically can potentially provide a viable solution. Translation teams could also consider the generation of multiple versions of the same sentence with different versions of a given term that is produced depending on specific sociodemographic information. Such an approach, however, increases the complexity of the measure and associated costs and could require the collection of data (e.g. religious background) that might not be directly related to the study itself and, as per research data governance, they should not be collected. In some instances, no equivalent sign exists for a particular written phrase or word. The commonly utilized collocation ‘quality of life’, a critical component in the translation of the WHOQOL (The World Health Organisation's Quality of Life Questionnaire; WHOQOL Group, 1998), does not exist in Libras, for example (Chaveiro et al., 2013). The pre-existing knowledge of the absence of this phrase in Libras helped the team prioritizing their efforts. Thoroughly investigating the questionnaire in question and considering particular words or phrases prior to translation commencing could help to expedite the process.

The structure, content and grammar used in questionnaires are different to that of prose text. For example, the use of pronouns in self-report scales posed a unique challenge to translation efforts. As is typical with a questionnaire, the respondent reads the instructions that preface the measure and responds to the subsequent statements in relation to their personal situation. Each item often relies on the use of “I” as a point of reference for the respondent to apply the statement to the way that they feel whilst completing the measure as it is read. Translating these items into sign language and changing the medium in which they are presented to the respondent, changes the focus of each statement and thus provides an area of contention. If a signer were to transliterate each item and retain the use of the pronoun

"I" as it is in the original version of the questionnaire, it could cause the respondent to become more susceptible to attributing the statement to that signer rather than what was actually required: namely, responding in a manner conducive to themselves (Rogers, Young, Lovell, & Evans, 2013). Ensuring that pronouns are translated appropriately is critical to preserving the items' initial meaning and protecting the validity of the questionnaire's score interpretations when presented in sign language. Rogers et al. (2015) suggested the use of the inclusion of "YOU WHAT?"[5] at the end of each item to communicate that the statement is a question directed to the responder of the questionnaire.

Similarly, the linguistic structures that certain questionnaires deploy can prove more difficult than others. Fellinger et al. (2005) observed how translating the Brief Symptom Inventory (BSI) (Derogatis & Spencer, 1982) was a lot less challenging than translating the WHOQOL (WHOQOL Group, 1998). The BSI, in its original written format, has a simpler linguistic structure to the WHOQOL allowing for a more straightforward interpreting process. Based on this finding, it is reasonable to suggest that the linguistic complexity of a measure be thoroughly considered before being selected for translation. Should a simpler, psychometrically sound version exist, the research team should evaluate whether this could be translated instead. A straightforward approach to assess the language accessibility of the original version is through the readability statistics of the text version. Not only would this streamline the process from a procedural perspective, but also allow for a more accessible measure for the deaf population to be generated. Generating the readability score of any text is possible by activating specific settings of frequently used word processors or via specialized software. In fact, researchers should consider using the readability scores of texts of any text-based scale regardless of whether it is to be linguistically/culturally adapted to sign language or is indeed intended for use in written format.

[5] By convention, in sign language glossing SMALL CAPS are used to represent signs.

Another linguistic barrier commonly found when presenting items to respondents related to the prefacing instructions and response anchors. A written self-report measure tends to follow a similar structure consisting of the title of the measure, instructions on how to respond and the individual items. For example, if responses range from 1 to 5, the prefacing information might state that 1 signifies "strongly disagree" whereas 5 signifies "strongly agree". As this information is written, it can be relied on as a constant referral point should the respondent need a reminder of the appropriate responses. As the written form is adapted into a visual format, the ability to refer back to both the prefacing instructions and scale anchoring becomes more problematic. This presents new problems for both the respondent and research team as it makes it more difficult to streamline the process of completing the measure in its visual format. For the respondent, retaining the response options in their memory whilst responding to each item introduces a new cognitive task and could potentially impact their ability to complete the measure appropriately (Berman et al., 2000). One workaround, in this case, relates to elements of each item, such as time scales, frames and instructions to be reinforced throughout the testing phase to mitigate the risk of falsely recalling potential responses (Roberts et al., 2015). Additionally, each item when converted into a video could have a 'replay' function so that the respondent can watch the item again if desired (Cornes et al., 2006).

Procedural Challenges and Facilitators

Procedurally, the most common issue was the use or type of technology and associated format errors that can occur. Each study utilized a different medium to accommodate the new measure, ranging from internet-based hosting (e.g. Rogers et al., 2014) to videotape (e.g. Brauer, 1992, 1993; Crowe, 2002; Glickman & Carey, 1993; Jones et al., 2006; Tweney & Hoemann, 1973). Relying on the use of a videotape appeared to be the most problematic approach to changing modality. As described by Jones et al. (2006), recording the items on videotape limited the editing options that the research team had available to

them. Attempting to edit the videotapes was both time-consuming and difficult owing to a lack of flexibility. Technical errors or malfunctions also hampered translation efforts in other scenarios (Tweney & Hoemann, 1973). Certain items were omitted from the final videotape, with this being attributed to the malfunction of equipment. The studies that have employed the use of videotape were conducted over 10 years ago and reflect a time when the use of internet-based hosting services was either not readily available or not regularly employed. With the Internet of Things and the use of Information Communication Technology (ICT) now dominating most research activities (Chatzidamianos & Parker, 2020), internet-based services are becoming more popular for hosting self-report measures in various formats and, in effect, this challenge may be less relevant now. Indeed, given the highly dispersed nature of the deaf population, hosting the new measure on the internet has been identified as a facilitator for the translation process (Rogers et al., 2014). Researchers should be mindful, however, that if a self-report measure is administered exclusively online it could limit its reach to only those who are ICT literate leaving parts of the deaf population who experience the digital divide unaccounted for (Yeratziotis & Van Greunen, 2013). Researchers should, therefore, adopt inclusive measures that are both human and technology-oriented and through which they could reach out to the grassroots of the deaf community via formal collaborations with deaf organizations, local deaf clubs, deaf schools etc.

Moving beyond the procedure of the translation/adaptation itself, a procedural issue emerged from the characteristics of the included papers. Specifically, those studies that followed an elaborate forward/backwards translation/adaptation were better positioned to identify and address possible linguistic, procedural and cultural issues compared to those that only followed a backward/forward approach or a translation of the written text to sign language or did not explicitly described the methodological approach to translation/adaptation. Notably, no study utilised cognitive interviews. Taken together, these

two points are significant for those embarking on translating/adapting written scales from written text to sign language. The established benefits of conducting cognitive interviews (Drennan, 2003; *Standards*, 2014) together with the benefits of iterative scale development procedures with input from the target population and multidisciplinary teams are expected to enhance the quality of the end product.

Cultural Challenges and Facilitators

Cultural barriers were reported frequently within the sample of studies. The way people think and behave is culturally informed. As such, concepts, phrases and statements included in the written version of a measure may not necessarily resonate with how deaf people experience the world. One of the most pervasive challenges encountered is related to the limited spoken language skills and general knowledge that some deaf respondents possessed. This is often attributed to the language deprivation that deaf people might have experienced in early life (Glickman, 2007; Glickman & Hall, 2018; Hall, 2017; Hall et al., 2017). Such challenges may lead to problems whilst field-testing instruments with participants, as some deaf individuals might struggle to understand elements of the questionnaire (Roberts et al., 2015). Related to this is the deaf community's general inexperience with surveys. As most measures and even more broad mainstream surveys tend to be published in a written format, deaf individuals often have no prior experience of having completed anything similar. This was particularly pertinent in deaf youth when asked about their overall limited life and survey experience (Berman et al., 2000). These issues are the by-product of the inequalities experienced by deaf people living in a world designed for hearing individuals and relate to more systemic societal challenges that are beyond the scope of this paper and cannot be immediately rectified. It is the responsibility of those developing and/or using written self-report measures with deaf people, however, to be mindful of the social challenges this particular population experiences and how these could invalidate the results.

The inclusion of items that do not directly apply to the deaf population, for instance, is one of the challenges identified in the construction of questionnaires. In one instance, the study authors opted against direct translations of items that referred to "hearing" or "talking" as they believed that deaf respondents would be deterred from responding accurately or completing the measure at all; instead, they chose to translate such concepts as "perceive through the ears" or INFORM DISCUSS (Montoya et al., 2004). Similarly, the Clinical Outcomes in Routine Evaluation Outcome Measures (Evans et al., 2000) specifically asks respondents about times when they have "talked" to others and felt that it was "too much". The authors note that deaf people might respond differently depending on how they understand 'talk' (Rogers, Young, Lovell, & Evans, 2013). For example, a deaf person may "strongly agree" if they perceive 'talk' to relate to communication in spoken language and, conversely, "strongly disagree" if perceived to relate to communication in sign language. To transliterate items like this would potentially lead to ambiguity in the new version of the measure and result in unintentional response errors in consequence. Contacting the original author of the measure for advice could aid the clarification of items that may otherwise be difficult to interpret in the target population (Montoya et al., 2004). Researchers should consider designing the self-report measure in such a way that allows access to the scale in both sign language and text (through closed captions, for instance). Aside from this, the research team could make a collaborative decision regarding which interpretation is most appropriate for the target measure and the population in question. Although none of the papers included in this review incorporated cognitive interviews at the prototyping phase of the translation/adaptation, in line with the *Standards* (2014) cognitive interviews should be used as they facilitate the identification of culturally informed challenges that can reduce the accessibility of the questionnaire content.

The sign language community are both small and tight-knit (Leigh et al., 2020). Identifying and recruiting appropriate individuals to sign the translated items can cause a potential conflict of interest because of the likelihood that respondents may recognize the signer who features on the screen. It is also likely that they may be well-acquainted with this individual and this, in turn, may influence the individual's response. Whether the signer is perceived as an "insider" or "outsider" in terms of their involvement with the deaf community could impact how the individual responds (Rogers, Young, Lovell, & Evans, 2013). Whilst this is a consideration for those translating for the deaf community, it is a barrier that is difficult to avoid entirely. Wahlqvist et al. (2016) found that the signer employed in one study contributed toward a high response rate because of their reputation and familiarity within the Deaf community. This should, therefore, remain a consideration throughout the translation process. The research team may consider consulting with participants before field testing to understand the degree to which they are familiar with the signer. The research team could seek to evaluate the specific benefits and drawbacks of identifying a well-known signer for the translation videos and the impact it could have on subsequent recruitment and truthfulness of responses.

Recommendations

In line with the above, a summary of key linguistic, procedural and cultural recommendations can be found in Table 3. An independent peer debriefer who is a bilingual deaf mental health professional has reviewed the results and recommendations of the review and has provided feedback that enabled the final refinement of the recommendations.

[insert Table 3 here]

Limitations

There are a few limitations in the current review. First, despite the equal waiting in the research question, the review identified slightly more challenges (n=79) than facilitators (n=75), a fact that became apparent during the quality appraisal process. As all processes

were designed to identify both challenges and facilitators equally, the uneven result can be attributed to the available data in the included papers. In a qualitative research project that explored the involvement of relatives in bipolar disorder, Chatzidamianos et al. (2015) attributed a similar tendency by their research participants to the possible effects of 'negative bias' (Ito et al., 1998). As negative bias was not the focus of the present review, no conclusive argument can be formed to account for the disproportionate reporting of challenges, and negative bias could be one of the possible tentative explanations.

Second, despite the diverse background and experience of the authors, not all sources of bias can be ruled out, as the authors pre-existing understanding of what constitutes a challenge/facilitator to the successful translation/adaptation would have a priori influenced the development of the data extraction sheet and the coding of the data and in effect the recommendations that derived from that. To that effect, the involvement of the independent bilingual deaf mental health professional who reviewed and commented on the results and recommendations, however, should have increased the objectivity by which the data are being reported.

Third, several cultural challenges are too deep-rooted in society to be mitigatable immediately. A prime example of this is the barrier alluding to deaf individuals' experiences with survey research or lack thereof. Paradoxically, deaf people's experiences of self-report measures will only improve once more research is focused on developing more accessible resources for this population. Challenges such as this will progressively become less prominent as research continues.

Fourth, the review does not establish a comparison of the challenges and facilitators depending on the psychological construct/phenomenon that each measure explored. By tabulating the constructs/phenomena and the number of corresponding challenges/facilitators, we attempted to address that issue, but the comparison was not meaningful for several

reasons: (a) the challenges/facilitators identified were not related to the construct itself, but to the written text being used to capture it (the issue relates to the equivalences that can(not) be achieved), the translation process or the cultural influences on the adaptation process, (b) reporting that the largest number of facilitators was, for instance, related to 'health risk behaviours' and the largest number of challenges concerned the 'diagnosis of mental health' adds little (if indeed anything) to the overall point of the work. This could be the by-product of the constructs that happened to have been translated as opposed to the constructs themselves. Had there been a comprehensive list of self-report measures of different diagnoses, for example, the comparison would have been more meaningful, (c) some authors, e.g. Fellinger, et al. (2005), referred to 3 constructs in the same paper simultaneously, which makes it impossible to allocate the specific challenges/facilitators to that vs the other construct and allocating them across all that were explored would have been an oversimplification.

Fifth, the coding of challenges and facilitators was performed by only one member of the review team which did not allow inter-rater reliability analysis. However, the relevance of such an analysis in qualitative synthesis, in general, is not clear and its role has been challenged in the past (Armstrong, 1997).

Sixth, the specific challenges and facilitators identified here could be dependent on the study design of each paper, an analysis we did not conduct. For instance, mixed designs might lend themselves more naturally to a more appropriate design to identify facilitators and identify and address challenges within the same study (e.g. qualitative data could provide clarity, checking for divergence, convergence, corroboration, explanation, elaboration, etc.). However, given that the present review focused on what hinders/enables the translation/adaptation procedures of self-report measures from text to sign and not on what research design produces more/fewer facilitators/challenges and of what type such an

analysis was beyond the scope of this review. What we did instead was to compare different methodological approaches to the translation/adaptation through which we were able to identify the approach that can enhance future translation/adaptation endeavours.

Finally, in the context of this review, it was not possible to evaluate the effectiveness of our recommendations. We hope that these recommendations will support future translation/adaptation efforts within which an evaluation of the recommendations could be performed.

Conclusion

In conclusion, adapting measures from a written format into sign language can be both time-consuming and challenging. This review has identified and synthesized recurrent problems that presented themselves during this process, along with suitable mitigating actions, in the hope that it will aid future adaptation efforts and thus subsequent accessibility for both clinicians and the academic community. Improved resources for the deaf population would undoubtedly contribute toward more comprehensive support and bridge the current gap in the measurement of psychological constructs in deaf people with implications on service planning and delivery.

References

Aanondsen, C. M., Jozefiak, T., Heiling, K., & Rimehaug, T. (2019). Validation of the Strengths and Difficulties Self-Report in Norwegian Sign Language. *Journal of Deaf Studies and Deaf Education, 25*(1), 91–104.

Acquadro, C., Conway, K., Giroudet, C., & Mear, I. (2012). *Linguistic Validation Manual for Health Outcome Assessments*. France.

American Educational Research Association, American Psychological Association, & National Council on Measurement in Education (Eds.). (2014). *Standards for educational and psychological testing*. Washington DC: American Educational Research Association.

Andrade, L. F., Borges, K. A., Ferreira, M. B. G., Felix, M. M. dos S., Castro, S. S. de, & Barbosa, M. H. (2018). Translation methods of instruments to sign language: an evidence-based proposal. *Texto & Contexto - Enfermagem*, *26*(4).

Andrade, L. F., Marquez, F. E., Ferreira, G. A., Pereira, S. R., Walsh, I. A. P. de, & Barbosa, M. H. (2019). Transcultural adaptation of the self-evaluation instrument of occupational operation for Brazilian Sign Language. *Texto & Contexto - Enfermagem*, *28*, e20180160.

Armstrong, D., Gosling, A., Weinman, J., & Marteau, T. (1997). The place of inter-rater reliability in qualitative research: An empirical study. *Sociology*, *31*(3), 597-606.

Attride-Stirling, J. (2001). Thematic networks: An analytic tool for qualitative research. *Qualitative Research, 1*, 385-405.

Berke, L., Huenerfauth, M., & Patel, K. (2019). Design and Psychometric Evaluation of American Sign Language Translations of Usability Questionnaires. *ACM Transactions on Accessible Computing (TACCESS)*, *12*(2), 6:1-6:43.

Berman, B. A., Eckhardt, E. A., Kleiger, H. B., Wong, G., Lipton, D. S., Bastani, R., & Barkin, S. (2000). Developing a tobacco survey for deaf youth. *American Annals of the Deaf*, *145*(3), 245–255.

Berry, J. A., & Stewart, A. J. (2006). Communicating with the Deaf During the Health Examination Visit. *The Journal for Nurse Practitioners*, *2*(8), 509–515.

Bisol, C. A., Sperb, T. M., Brewer, T. H., Kato, S. K., & Shor-Posner, G. (2008). HIV/AIDS knowledge and health-related attitudes and behaviors among deaf and hearing adolescents in southern Brazil. *American Annals of the Deaf*, *153*(4), 349–356.

Brauer, B. A. (1992). The Signer Effect on MMPI Performance of Deaf Respondents. *Journal of Personality Assessment*, *58*(2), 380–388.

Brauer, B. A. (1993). Adequacy of a translation of the MMPI into American Sign Language for use with deaf individuals: Linguistic equivalency issues. *Rehabilitation Psychology*, *38*(4), 247–260.

Brislin, R. W. (1970). Back-Translation for Cross-Cultural Research. *Journal of Cross-Cultural Psychology*, *1*(3), 185–216.

Cabral, L., Muhr, K., & Savageau, J. (2013). Perspectives of People Who Are Deaf and Hard of Hearing on Mental Health, Recovery, and Peer Support. *Community Mental Health Journal*, *49*(6), 649–657.

Chatzidamianos, G. (2015). The implications of impaired language on case management and clinical assessment in Deaf adults with psychosis. *22nd International Congress on the Education of the Deaf (ICED 2015).* Athens: University of Patras.

Chatzidamianos, G., Lobban, F., & Jones, S. (2015). A qualitative analysis of relatives', health professionals' and service users' views on the involvement in care of relatives in Bipolar Disorder. *BMC psychiatry*, *15*(1), 1-12.

Chatzidamianos, G., & Fletcher, I. (2019). Wellbeing and the communication of emotions in healthcare of deaf people. *Emotions 2019: 7th International Conference on Emotions, Well-Being, and Health*. Retrieved from www.eiseverywhere.com/ehome/emotions2019/Welcome/

Chatzidamianos, G., Fletcher, I., Wedlock, L., & Lever, R. (2019). Clinical communication and the 'triangle of care' in mental health and deafness: Sign language interpreters' perspectives. *Patient Education and Counseling*, *102*(11), 2010–2015.

Chatzidamianos, G., McCarthy, R. A., Du Feu, M., Rosselló, J., & McKenna, P. J. (2018). Language abnormality in deaf people with schizophrenia: a problem with classifiers. *Cognitive Neuropsychiatry*, *23*(4), 229–241.

Chatzidamianos, G., & Parker, R. J. (2020). Using information and communication technologies for health research. In C. Walshe & S. G. Brearley (Eds.), *Handbook of Theory and Methods in Applied Health Research: Questions, Methods and Choices* (pp. 284–303). Cheltenham, UK: Edward Elgar Publishing Limited.

Chaveiro, N., Duarte, S. B. R., Freitas, A. R. de, Barbosa, M. A., Porto, C. C., & Fleck, M. P. de A. (2013). Instruments in Brazilian Sign Language for assessing the quality of life of the deaf population. *Revista De Saude Publica*, *47*(3), 616–623.

Cieśla, K., Lewandowska, M., & Skarżyński, H. (2016). Health-related quality of life and mental distress in patients with partial deafness: preliminary findings. *European Archives of Oto-Rhino-Laryngology: Official Journal of the European Federation of Oto-Rhino-Laryngological Societies (EUFOS): Affiliated with the German Society for Oto-Rhino-Laryngology - Head and Neck Surgery*, *273*(3), 767-776.

Cornes, A., & Brown, P. M. (2012). Mental Health of Australian Deaf Adolescents: An Investigation using an Auslan Version of the Strengths and Difficulties Questionnaire. *Deafness & Education International*, *14*(3), 161–175.

Cornes, A., Rohan, M. J., Napier, J., & Rey, J. M. (2006). Reading the signs: impact of signed versus written questionnaires on the prevalence of psychopathology among deaf adolescents. *Australian and New Zealand Journal of Psychiatry*, *40*(8), 665–673.

Crowe, T. V. (2002). Translation of the Rosenberg Self-Esteem Scale into American Sign Language: A principal components analysis. *Social Work Research*, *26*(1), 57–63.

Derogatis, L. R., & Spencer, P. M. (1982). *The Brief Symptom Inventory (BSI): Administration, and Procedures Manual-I*. Baltimore, MD.

Drennan, J. (2003). Cognitive interviewing: verbal data in the design and pretesting of questionnaires. *Journal of Advanced Nursing*, *42*(1), 57–63.

du Feu, M., & Chovaz, C. (2014). *Mental health and deafness*. Oxford University Press.

Evans, C., Mellor-Clark, J., Margison, F., Barkham, M., Audin, K., Connell, J., McGrath, G. (2000). CORE: Clinical Outcomes in Routine Evaluation. *Journal of Mental Health, 9*, 247–255.

Fellinger, J., Holzinger, D., Dobner, U., Gerich, J., Lehner, R., Lenz, G., & Goldberg, D. (2005). An innovative and reliable way of measuring health-related quality of life and mental distress in the deaf community. *Social Psychiatry and Psychiatric Epidemiology*, *40*(3), 245–250.

Friedner, M., & Kusters, A. (2020). Deaf Anthropology. Annual Review of Anthropology, *49*(1), 31–47.

Glickman, N. S. (2007). Do You Hear Voices? Problems in Assessment of Mental Status in Deaf Persons With Severe Language Deprivation. *Journal of Deaf Studies and Deaf Education*, *12*(2), 127–147.

Glickman, N. S., & Carey, J. C. (1993). Measuring deaf cultural identities: A preliminary investigation. *Rehabilitation Psychology*, *38*(4), 275–283

Glickman, N. S., & Gulati, S. (2003). *Mental Health Care of Deaf People: A Culturally Affirmative Approach*: EBSCOhost. Mahwah, N.J.: Routledge.

Glickman, N. S., & Hall, W. C. (2018). *Language deprivation and deaf mental health*. New York and London: Routledge.

Graybill, P., Aggas, J., Dean, R. K., Demers, S., Finigan, E. G., & Pollard, R. Q. (2010). A Community-Participatory Approach to Adapting Survey Items for Deaf Individuals and American Sign Language. *Field Methods*, *22*(4), 429–448.

Grote, H., & Izagaren, F. (2020). Covid-19: The communication needs of D/deaf healthcare workers and patients are being forgotten. *BMJ (Clinical Research Ed.)*, 369, m2372.

Hall, D. A., Domingo, S. Z., Hamdache, L. Z., Manchaiah, V., Thammaiah, S., Evans, C., … NETwork, Tin. R. (2018). A good practice guide for translating and adapting hearing-

related questionnaires for different languages and cultures. *International Journal of Audiology*, *57*(3), 161–175.

Hall, W. C. (2017). What You Don't Know Can Hurt You: The Risk of Language Deprivation by Impairing Sign Language Development in Deaf Children. *Maternal and Child Health Journal*, *21*(5), 961–965.

Hall, W. C., Levin, L. L., & Anderson, M. L. (2017). Language deprivation syndrome: a possible neurodevelopmental disorder with sociocultural origins. *Social Psychiatry and Psychiatric Epidemiology*, *52*(6), 761–776.

Harrison, R., Jones, B., Gardner, P., & Lawton, R. (2021). Quality assessment with diverse studies (QuADS): an appraisal tool for methodological and reporting quality in systematic reviews of mixed- or multi-method studies. *BMC Health Services Research*, *21*(1), 144.

Haug, T., & Mann, W. (2008). Adapting Tests of Sign Language Assessment for Other Sign Languages—A Review of Linguistic, Cultural, and Psychometric Problems. *The Journal of Deaf Studies and Deaf Education*, *13*(1), 138–147.

Herdman, M., Fox-Rushby, J., & Badia, X. (1997). 'Equivalence' and the translation and adaptation of health-related quality of life questionnaires. *Quality of Life Research*, *6*, 237–247.

Horne, N., & Pennington, J. (2010). The role of the Nurse Specialist in the highly specialized field of Mental Health and Deafness. *Journal of Psychiatric and Mental Health Nursing*, *17*(4), 355–358.

Iezzoni, L. I., Davis, R. B., Soukup, J., & O'Day, B. (2003). Quality Dimensions That Most Concern People With Physical and Sensory Disabilities. *Archives of Internal Medicine*, *163*(17), 2085.

Ito, T. A., Larsen, J. T., Smith, N. K., & Cacioppo, J. T. (1998). Negative information weighs more heavily on the brain: The negativity bias in evaluative categorizations. *Journal of Personality and Social Psychology*, *75*(4), 887–900.

Jones, E. G., Mallinson, R. K., Phillips, L., & Kang, Y. (2006). Challenges in language, culture, and modality: translating English measures into American sign language. *Nursing Research*, *55*(2), 75–81.

Landis, J., & Koch, G. (1977). The measurement of observer agreement for categorical data. Biometrics, *33*, 159-174.

Leigh, I. W., Andrews, J. F., & Harris, R. L. (2020). *Deaf culture: Exploring deaf communities in the United States*. (2nd ed.). San Diego, CA: Plural Publishing.

Lesch, H., Burcher, K., Wharton, T., Chapple, R., & Chapple, K. (2019). Barriers to healthcare services and supports for signing deaf older adults. *Rehabilitation Psychology*, *64*(2), 237–244.

Levine, J. (2014). Primary care for deaf people with mental health problems. *British Journal of Nursing*, *23*(9), 459–463.

Levinger, M., & Ronen, T. (2008). Is it really clear? Adapting research tools for the needs of the deaf population. *Journal of Social Work*, *8*(4), 399–430.

Maneesriwongul, W., & Dixon, J. K. (2004). Instrument translation process: a methods review. *Journal of Advanced Nursing*, *48*(2), 175–186.

McArthur, A., Klugárová, J., Yan, H., & Florescu, S. (2015). Innovations in the systematic review of text and opinion. *International Journal of Evidence-Based Healthcare*, *13*(3), 188–195.

McKee, M., Barnett, S. L., Block, R. C., & Pearson, T. A. (2011). Impact of Communication on Preventive Services Among Deaf American Sign Language Users. *American Journal of Preventive Medicine*, *41*(1), 75–79.

McKee, M., Paasche-Orlow, M. K., Winters, P. C., Fiscella, K., Zazove, P., Sen, A., & Pearson, T. (2015). Assessing Health Literacy in Deaf American Sign Language Users. *Journal of Health Communication*, *20*(2), 92–100.

Montoya, L. A., Egnatovitch, R., Eckhardt, E., Goldstein, M., Goldstein, R. A., & Steinberg, A. G. (2004). Translation Challenges and Strategies: The ASL Translation of a Computer-Based, Psychiatric Diagnostic Interview. *Sign Language Studies*, *4*(4), 314–344.

Moore, K., Wright, B. J. D., Moore, D., Ogden, R., & Rogers, K. (2013). Overcoming the challenges of translating mental health instruments into sign languages. *International Journal on Mental Health and Deafness*, 20–29.

Morere, D. A. (2013). Methodological issues associated with sign- Based neuropsychological assessment. *Sign Language Studies*, *14*(1), 8–20

Movallali, G., Musavi, Z., & Hakimi-Rad, E. (2018). Feeling of Loneliness in Deaf Adolescents: the Effect of an Online Life Skills Program. *European Journal of Social Science Education and Research*, *5*(1), 121–129.

Neves, J. T. P. das, Zatti, C., Severo, C., Malgarim, B. G., & Freitas, L. H. M. (2020). Psychoanalytic Psychotherapy with Deaf Patients: A Qualitative Study of Characteristics and Technical Adaptations in Clinical Practice. *British Journal of Psychotherapy*, *36*(3), 445–463.

Page, M. J., McKenzie, J., Bossuyt, P., Boutron, I., Hoffmann, T., & Mulrow, C. D. (2020). The PRISMA 2020 statement: an updated guideline for reporting systematic reviews. MetaArXiv. 2020.

Panzer, K., Junghyun, P., Pertz, L., & McKee, M. (2020). Teaming Together to Care for Our Deaf Patients: Insights from the Deaf Health Clinic. *Journal of the American Deafness & Rehabilitation Association*, *53*(2), 60–77.

Pardo-Guijarro, M. J., Woll, B., Moya-Martínez, P., Martínez-Andrés, M., Cortés-Ramírez, E. E., & Martínez-Vizcaíno, V. (2013). Validity and reliability of the Spanish sign language version of the KIDSCREEN-27 health-related quality of life questionnaire for use in deaf children and adolescents. *Gaceta Sanitaria*, *27*(4), 318–324.

Paul, M., & Leibovici, L. (2014, February). Systematic review or meta-analysis? Their place in the evidence hierarchy. *Clinical Microbiology and Infection*, *20*, 97–100.

Pereira, P. C. A., & Fortes, P. A. de C. (2010). Communication and information barriers to health assistance for deaf patients. *American Annals of the Deaf*, *155*(1), 31–37.

Pollard, R. Q. (1996). Professional psychology and deaf people. The emergence of a discipline. *The American Psychologist*, *51*(4), 389–396.

Pollard, R. Q., & Barnett, S. (2009). Health-related vocabulary knowledge among deaf adults. *Rehabilitation Psychology*, *54*(2), 182–185.

Qi, S., & Mitchell, R. E. (2012). Large-Scale Academic Achievement Testing of Deaf and Hard-of-Hearing Students: Past, Present, and Future. *Journal of Deaf Studies and Deaf Education*, *17*(1), 1–18.

Quer, J., & Steinbach, M. (2019). Handling Sign Language Data: The Impact of Modality. *Frontiers in Psychology*, *10*, 483.

Reeves, D., & Kokoruwe, B. (2005). Communication and communication support in primary care: A survey of deaf patients. *Audiological Medicine*, *3*, 95–107.

Roberts, S., Wright, B., Moore, K., Smith, J., Allgar, V., Tennant, A., … Rogers, K. (2015). Translation into British Sign Language and validation of the Strengths and Difficulties Questionnaire. *Health Services and Delivery Research*, *3*(2), 1–96.

Rogers, K. D., Dodds, C., Campbell, M., & Young, A. (2018). The validation of the Short Warwick-Edinburgh Mental Well-Being Scale (SWEMWBS) with deaf British sign language users in the UK. *Health and Quality of Life Outcomes*, *16*(1), 145.

Rogers, K. D., Evans, C., Campbell, M., Young, A., & Lovell, K. (2014). The reliability of British Sign Language and English versions of the Clinical Outcomes in Routine Evaluation--Outcome Measure with d/Deaf populations in the UK: an initial study. *Health & Social Care in the Community*, *22*(3), 278–289.

Rogers, K. D., Pilling, M., Davies, L., Belk, R., Nassimi-Green, C., & Young, A. (2016). Translation, validity and reliability of the British Sign Language (BSL) version of the EQ-5D-5L. *Quality of Life Research: An International Journal of Quality of Life Aspects of Treatment, Care and Rehabilitation*, *25*(7), 1825–1834.

Rogers, K. D., Young, A., Lovell, K., Campbell, M., Scott, P. R., & Kendal, S. (2013). The British Sign Language Versions of the Patient Health Questionnaire, the Generalized Anxiety Disorder 7-Item Scale, and the Work and Social Adjustment Scale. *The Journal of Deaf Studies and Deaf Education*, *18*(1), 110–122.

Rogers, K. D., Young, A., Lovell, K., & Evans, C. (2013). The challenges of translating the clinical outcomes in Routine Evaluation-Outcome Measure (CORE-OM) into British Sign Language. *Journal of Deaf Studies and Deaf Education*, *18*(3), 287–298. 02

Saldana, J. (2013). T*he coding manual for qualitative researchers* (2nd ed.). Thousand Oaks, CA: Sage.

Samady, W., Samady, W., Sadler, G. R., Nakaji, M., Malcarne, V. L., Trybus, R., & Athale, N. (2008). Translation of the multidimensional health locus of control scales for users of American sign language. *Public Health Nursing (Boston, Mass.)*, *25*(5), 480–489.

Sign Health. (2014). *A Report into the Health of Deaf People in the UK.* London: SignHealth

Sirriyeh, R., Lawton, R., Gardner, P., & Armitage, G. (2012). Reviewing studies with diverse designs: The development and evaluation of a new tool. *Journal of Evaluation in Clinical Practice*, *18*, 746–752.

Skyer, M. E. (2020). Invited Article: The Bright Triad and Five Propositions: Toward a Vygotskian Framework for Deaf Pedagogy and Research. *American Annals of the Deaf, 164*(5), 577–591.

Smith, S. R., & Samar, V. J. (2016). Dimensions of Deaf/Hard-of-Hearing and Hearing Adolescents' Health Literacy and Health Knowledge. *Journal of Health Communication, 21*(2), 141–154.

Tweney, R. D., & Hoemann, H. W. (1973). Back Translation: A Method for the Analysis of Manual Languages. *Sign Language Studies, 2*(1), 51–72.

Veritas Health Innovation. (n.d.). *Covidence systematic review software*. Retrieved from www.covidence.org

Vos, T., Barber, R. M., Bell, B., Bertozzi-Villa, A., Biryukov, S., Bolliger, I., … Murray, C. J. (2015). Global, regional, and national incidence, prevalence, and years lived with disability for 301 acute and chronic diseases and injuries in 188 countries, 1990–2013: a systematic analysis for the Global Burden of Disease Study 2013. *The Lancet, 386*(9995), 743–800.

Wahlqvist, M., Möller, K., Möller, C., & Danermark, B. (2016). Physical and psychological health, social trust, and financial situation for persons with Usher syndrome type 1. *British Journal of Visual Impairment, 34*(1), 15–25.

WHOQOL Group. (1998). Development of the World Health Organization WHOQOL-BREF Quality of Life Assessment. *Psychological Medicine, 28*(3), 551–558.

Yeratziotis, G., & Van Greunen, D. (2013). Making ICT accessible for the deaf. *2013 IST-Africa Conference & Exhibition*, 1–9. IEEE.

Table 1

Quality appraisal of opinion papers and texts

No	Author	Is the source of the opinion clearly identified?	Does the source of opinion have standing in the area of expertise?	Are the interests of the relevant population the central focus of the opinion?	Is the stated opinion the result of an analytical process, and is there logic in the opinion expressed?	Is there reference to the extant literature?	Is there any incongruence with the literature/sources logically defended?
1	Graybill et al., 2010	Yes	Yes	Yes	Yes	Yes	No
2	Montoya et al., 2004	Yes	Yes	Yes	Yes	Yes	No
3	Rogers, Young, Lovell, & Evans, 2013	Yes	Yes	Yes	Yes	Yes	No

Table 2

Linguistic, Procedural, Cultural Challenges and Facilitators

No	Authors	Methodological approach to adaptation	Facilitators	Challenges to translation		
				Linguistic	**Procedural;**	**Cultural**
1	Aanondsen et al., 2018 Norway	***Elaborate*** **Forward translation:** Two bilingual deaf native NSL users with university degrees in teaching **Review panel:** Forward translators, clinical psychologist, colleague with graduate degree in medicine specialising in child psychiatry & a consultant with a Master's degree in language & fluent in NSL **Focus group:** Teachers from local deaf school (Deaf, hearing & CODA) **Backward translation:** Two hearing SL interpreters	Present both the written and SL version to participants in a combined online fashion	Prosocial behavior items non-significant, meaning further review would be required	Not reported	Not reported
2	Andrade et al., 2019 Brazil	***Elaborate*** **Forward translation:** "based on the criteria: bilingual or bicultural men & women, deaf community participants, certified interpreters, LIBRAS teachers, deaf people or health professional – 5 translators, deaf & hearing" **Preparation of V2:** "…three research professors with The minimum degree of master" **Backward translation:** "A certified hearing, & a deaf professor of LIBRAS, certified" **Review judges:** 5 judges, PhD researchers, fluent in LIBRAS, among deaf & hearing	"…judges suggested the inclusion of reflective signs at the beginning of some questions added to the replacement of the pronouns translated to the third person "you" and "yours", for "me" and "my".	Use of pronouns such as "I" and "you" were misleading and changed Old signs or significant linguistic variations were replaced, or two signs were used.	Not reported	Not reported
3	Berke et al., 2019 USA	***Elaborate*** **ASL-SUS Forward translation:** Fluent native signer who was also	Not reported	Use of "DO-DO" sign was not understood and sign for "ACTIVITY" was used instead	Not reported	Not reported

		a doctoral student of computing, fluent native signer masters student in computing, faculty member with PhD in computing & learnt ASL in adult life First backward translation 9 advanced students who studied ASL interpreting. 3 students reported having deaf family members, 1 self-reported as CODA & the remaining students had a range of experience with ASL between 3-8 years **Second backward translation:** 10 new advanced students studying ASL interpreting ASL-NPS. Same team as ASL-SUS, but with a new deaf masters student owing to the previous student graduating **First backward translation:** Focus group; 2 professional certified ASL interpreters & 2 deaf students **Second backward translation:** 12 students from Bachelor's degree program for ASL interpreting		Use of the sign for "AWKWARD" was too fast and was slowed down Use of "OVERWHELM" could be interpreted as the human at fault, not product Avoidance of the ASL sign "SUGGEST" as used differently to the English use of "recommend" ASL sign for "INFORM" did not convey recommend and suggested "COME-COME" be added Translation of "extremely likely" to ASL sign for "MUST" was problematic as perceived as deontic verb – used "BE SURE INFORM" not "MUST INFORM" Whilst "THUMBS UP" indicates approval, concerns that this could be perceived as ASL sign for "TEN" - "A-OK" used instead		
4	Berman et al., 2000 USA	***Forward-backward only*** **Forward translation:** Project director, deaf consultant (native signer), deaf interpreter who primarily communicates using ASL **Backward translation:** Bilingual individual who was unfamiliar with written English measures	Reduce the number of multiple-choice questions where appropriate Support of researchers and members of the community Researchers had to mark precise times to enable easier editing	Difficulty when using responses such as "strongly agree, somewhat agree" as problematic in ASL, meaning responses had to be converted into "yes/no"	Where written English would display all responses together, responses must be signed sequentially and then retained in memory by respondent Media consultants could not distinguish where questions/responses started & stopped when editing	Basic concept of "survey" or "survey research" may be unfamiliar to deaf youth
5	Bisol et al., 2008 Brazil	***Forward only*** **Translation:** One male & one female deaf teacher who were both fluent signers, assisted by an	Focus groups completed prior to study to understand best method for participants	Not reported	Not reported	Sign language skills were not verified by research team, which could explain

		official SL interpreter & the lead author				incomprehensible open-text responses
6	Brauer 1992 USA	***Not reported***	Add text to account for colloquialisms in sign language Information should be presented in a psychologically professional manner, especially for sensitive items	Not reported	MMPI is 566 item - shortened version selected to reduce running time	Not reported
7	Brauer 1993 USA	***Forward-backward only*** **First stage (forward):** 3 deaf bilinguals: PhD psychologist familiar with MMPI, M.A. linguist & an RA with MA in counselling **Second stage (backward):** 3 non-Deaf individuals unfamiliar with the MMPI **Comparison:** 2 deaf bilingual professionals	Use of second person pronouns Items should be culturally, conceptual and psychological equivalent Incorporate the signed version with Pidgin Signed English to reach the majority of the literate deaf population	Not reported	Not reported	Not reported
8	Chaveiro et al., 2013 Brazil	***Elaborate*** **Forward translation:** revision by bilingual team, re-evaluation of second back translation: 4 children of deaf parents, without hearing impairment, fluent in Libras; checked by project team **First-back translation:** **s**yntactic/semantic analysis, second-back translation: interpreter (not involved in project team) Focus groups: 3 focus groups: deaf individuals (n = 9) 2. Family members of deaf individuals (n = 6) 3. Libras interpreters (n = 6) **Revision** by monolingual: 2 deaf individuals with Libras as L1	Use of individuals fluent in Libras; Bilingual group should have experience of deaf culture Before back translation, a synthesized version should be produced Back translation should not be merely a transcription Signers articulating clearly with good facial expression Development should be noted	Sign for "quality of life" required as no sign for QoL in Libras Ungrammatical items were found in Libras owing to direction of expressions (exaggerated or inexpressive), missing the context and lack of fluidity when executing signs in Libras	Not reported	Not reported
9	Cornes & Brown 2012 Australia	***Forward-backward only*** **Forward translation:** First named author (fluent in Auslan) & accredited Auslan interpreter (also native SL user) **Backward translation:** 2 professionals who were native SL users, one deaf & one hearing &	Translation process repeated until linguistic equivalency had been achieved Items revised to reflect differing educational backgrounds	Not reported	Not reported	Not reported

		had no knowledge of written English versions				
10	Cornes et al., 2006 Australia	***Forward-backward only*** **Forward translation:** Professionally accredited Auslan interpreter **Backward translation:** Two native SL users, one deaf & one hearing	Facility to replay the video if the participant desires	Not reported	Written version of YSR allows free-text responses - not possible with the Auslan version	Signing deaf children may have a limited vocabulary regarding affective states
11	Crowe 2002 USA	***Forward-backward only*** **Forward translation:** 1 female prelingually deaf bilingual individual employed as an ASL instructor **Backward translation:** A professional interpreter unfamiliar with RSES Stage 3 (comparison) Two individuals: one deaf bilingual & one hearing bilingual	Not reported	General translation error proposed as a reason for unexpected results	Not reported	Not reported
12	Fellinger et al., 2005 Austria	***Forward-backward only*** **Forward translation**: 10 leaders of deaf clubs in Upper Austria; psychiatrist, linguist and interpreter check **Backward translation:** 3 independent sign language interpreters, checked by linguist	Not reported	BSI was more successful due to simpler linguistic structure; WHOQOL more complex	Not reported	Respondents had limited sign language Deaf "way of thinking" – influenced by visual modality of SL and communication deprivation
13	Glickman & Carey 1993 USA	***Forward-backward only*** **Forward translation:** Native deaf signer who was a deaf person from a deaf family who acquired ASL from birth **Backward translation:** ASL/English interpreter, unaware of the original English version	Not reported	Title amended as "Deaf Identity Development Scale" difficult to translate into ASL	Not reported	Not reported
14	Graybill et al., 2010 USA	***Forward-backward only*** **Translation working group** (TWG) 6 members affiliated with the NCDHR and/or deaf Health Community Committee **Backward Translation** Bilingual individual unfamiliar with the source material	Ability to switch between several signers useful so respondent has a choice All TWG meetings were conducted in ASL to align with practices in deaf culture as well as maximizing visual media and clear turn-taking when communicating Minutes were documented from each meeting and circulated rapidly to reduce the risk of error	Strict adherence to ASL script was sometimes difficult, as the signers had different opinions on how certain questions should be signed New terminology difficult to sign e.g. "urgent care centre" The word "drink", alluding to an alcoholic beverage in English, is more difficult to convey in ASL, therefore, adaptations were required. A similar instance was found for	Not reported	Given that healthcare communication with deaf persons is often inadequate, translations were based more on deaf persons experiences rather than what they had been "told"

			Strive to translate the meaning rather than a transliteration of the written English Consider the translations for the widest range of deaf persons e.g. age, gender, education, etc. Avoid improving source material even when logic in the statement does not appear clear and directly applicable in SL Inclusion of video dictionary for specialist terms Signers should follow a video ASL script – not an ASL gloss or written English – to maintain accuracy Time and effort must be expended on the translation team, with bilingualism and cultural experience critical Research team should record all progress in the same target language e.g. ASL Fluency in a language does not mean that the signer will be comfortable signing directly from a script Presence of TWG coach at all recordings to ensure accurate reading and adherence to script	"suicide" that cannot be used generally in ASL Some questions were segregated e.g. "How old were you when you smoked your first whole cigarette?" – this presumes the individual has smoked before, therefore the embedded meaning was disentangled Transformation of "I" and "my" to "YOU" and "YOUR" to maximize dialogic nature Amendment of some responses as in written English surveys, responses are presented simultaneously whereas ASL video means sequential, restricting participant from skimming potential responses		
15	Jones et al., 2006 USA	***Elaborate*** **Principal investigator**: Hearing, familiar with SL & considerable experience of deaf community **Co-investigator:** Fluent in SL & experience in both research & practice with deaf persons **Deaf actor:** Deaf man in the community who was known for fluency/clarity in SL & facility with English **Translation team:** Bilingual adults, some with SL as first language, some with English as the first language. Consultants who reflected cultural and linguistic	Use of both individual and group reviews as regional variations in sign & colloquialisms considered Feedback from deaf reviewers ensured videotape was not condescending to deaf community	As ASL is dynamic, same signer may alter the translation of an item slightly each time – "gloss" was created to maintain consistency	Use of videotape limiting, as editing was time-consuming and lacked flexibility Difficulties in recruiting enough bilingual people to take both versions Lighting on VT and transition between items was distracting	Deaf consultants felt repetitive nature of answer format was inappropriate – actor signed responses after every item – they felt this was insulting and deaf respondents would remember directions

		background of the deaf population **Individual reviewer:** Professional interpreter whose first language was SL				
16	Levinger & Ronen 2008 Israel	***Forward-backward only*** **Forward translation:** "Skilled sign language translator" – hearing person renowned in the deaf community **Backward translation:** 4 deaf judges: 2 female deaf judges with hearing parents, 2 male deaf judges with deaf parents; all use sign as primary language	Participants "overwhelmingly" selected written language over a signed video Selecting a well-respected, well-known translator helped the measures to be "clear" Two of the judges were members of the same deaf community recruited from – fostered reliable communication	Not reported	Not reported	Authors suggest that translators notoriety in the deaf community could actually work the opposite way and could have impeded their selection of questionnaire type
17	McKee et al., 2015 USA	***Not reported***	Make the final ASL version available with English captions, audio and a signing video for a variety of audiences.	Not reported	Not reported	Not reported
18	Montoya et al., 2004 USA	***Elaborate*** **Translation team members**: Bilingual, bicultural researchers, interpreters & mental health clinicians **Review committee:** 2 other study authors, a psychiatrist, masters-level mental health clinician & researcher with experience of working with deaf patients Both teams had a certified deaf interpreter, study author and certified hearing interpreter	Offer the questionnaire in a number of languages and modalities, e.g. ASL, signed English, captioned in written English Offer options for the participant to replay where desired Avoiding complex sentences with multiple clauses Divide references to time into shorter units Use two translation teams with a wide scope of skills and experience Use of a "topic box" as a standalone video segment indicating nature of question Empty text field allowed respondents to give reasonings behind their answer, but didn't pressure/force them into responding if they were not comfortable with their English Skills Use a second monitor to combat issues of signs which move along the z-axis to evaluate accuracy	Concepts such as time, duration, English idioms were all difficult to translate e.g. "feeling on edge" also phrases used commonly in English culture such as "hearing voices" Difference in terms used in deaf culture e.g. issues translating "panic attack" was cumbersome Challenges of different intellect and regional variations in common words in ASL e.g. "hospital" in Eastern part of New York is unique to the area English category words not directly translatable, with same scope, into ASL e.g. "have you ever hit your husband/wife?" – ASL translation more literal in terms of SLAP, PUNCH, PUSH, STRIKE Facial expressions, speed of sign, etc. all impact upon the signs subsequent meaning Time within time periods extremely difficult to convey e.g. "two-week period in your entire lifetime"	Signs that move perpendicular to the signer, moving toward the camera, were difficult to perceive accurately Some members of team apprehensive about free text response and impact on respondents' attitude	Translating items that explicitly ask about "hearing" were not translated directly, as it was thought this would put off respondents and they may avoid responding

			Contact original authors to understand their intended meaning when finding difficult translating category words Capitalize upon ASL syntactic features such as referential indicators & topicalization to overcome complex English concepts	Translating items that were complex in written English produces equivalent complex ASL version Distinguishing between related but different psychological states e.g. "restless", "edgy" and "jumpy" – scrutinizing English differences meant signing them along a continuum Open-ended questions were challenging as there is no stipulation as to which unit the respondent should use		
19	Moore et al., 2013 UK	***Elaborate*** **Forward translation:** 3 bilingual translators **Backward translation:** 3 bilingual translators blind to original versions **Review**: "Expert panel" **Focus groups**: Five deaf young people (young person version) Five deaf adults (adult version) 20All use BSL as their first language "…equal numbers of clinical psychologists & those experienced in translation work across the teams"	Translation teams with varying ages essential given different questionnaire versions Having deaf translators on BOTH forward and backward teams owing to differing cultures Balance of academic and lay persons on each team Number of versions recorded with different signers to avoid potential transference issues Important to film the focus groups to capture full extent of discussions	Not reported	Not reported	Whilst important to have service users involved, it may be that those involved here had a wider and more complex vocabulary than the average deaf person Many deaf people grow up using different methods of communication: those fluent in SL were comfortable with translations, whereas those who also use oral English found them difficult
20	Pardo-Guijarro et al., 2013 Spain	***Elaborate*** **Forward translation:** 3 bilingual deaf adults, working alongside an LSE interpreter **Backward translation:** Another LSE interpreter & post- lingually deaf bilingual person (not previously involved) **Clarification of first translation:** Items reassessed by a bilingual deaf person & discussed with interpreted involved in forward translation	A specific web tool was designed to host the questionnaire to ensure that it was fully accessible Preserved same structure from written to LSE to improve compatibility	Not reported	Not reported	Not reported

		Second back translation: Two additional translators: one was deaf & one with moderate hearing loss; both were bilingual **Signers for video:** A female Spanish/LSE interpreter and a hearing young male whose father was deaf & who was bilingual in Spanish & LSE				
21	Roberts et al., 2015 UK	***Elaborate*** **Forward translation:** 3 bilingual translators **Backward translation:** 3 bilingual translators blind to original versions **Review:** "Expert panel" **Focus groups:** Five deaf young people (young person version) Five deaf adults (adult version) All use BSL as their first language "…equal numbers of clinical psychologists & those experienced in translation work across the teams"	Important to have a translation team from a range of backgrounds due to lexical differences Varying ages also important owing to different versions of measures available As long as presenter is clear and comfortable in their signing, age and gender had limited relevance Pre-pilot a primary translation as signing ability of 11-16 year olds can be highly varied Important for the signer presenting items to sign in an attitudinally neutral way with paralinguistic features avoided Suggested that the "YOU" at the end of each sentence is contextualized e.g. "YOU HAVE?" rather than "YOU WHAT?" more generically Avoid narrowing translation where the original word is a category word and can be open to interpretation Time frames, scales and instructions may need to be reinforced, and it may be necessary to give a specific contextual placement in each case	Issues with the use of severity anchors (true, certainly true, somewhat true) as this is normally conveyed in SL through facial expression Including a feature on the end denoting "YOU WHAT?" to indicate the question is directed to the respondent (finishing each statement with the index finger pointing outward with head tilted to indicate questioning) was deemed to be confusing Sign placement required additional thought e.g. clingy – implicit in English, whereas in SL requires direction (placement)	Written questionnaires present instructions at the top of the page – these can be constantly referred back to. However, with visual content, these may need to be reiterated with each piece of content to ensure validity	The range of expertise in the translation teams may not actually reflect the deaf community at large, using more expansive lexical. Many deaf people grow up using different methods of communication and their language is developed in a naturalistic and not necessarily grammatically correct way
22	Rogers, Young, Lovell, Campbell, et al., 2013 UK	***Elaborate*** **Forward translation:** All members of the deaf community; 3 woman, 2 men and included one deaf qualified BSL/English interpreter, 1 deaf clinical psychologist, 1	Internet hosting allowed research team to reach a highly dispersed population and ensured a fixed translation	Not reported	Not reported	Two components of depression in analysis – suggests that depression may have two distinct facets in the deaf population

		deaf mental health support worker and 2 lay deaf people **Backward translation:** 2 deaf individuals (not previously involved) **"Work-through"**: 5 BSL users (not previously involved)				
23	Rogers, Young, Lovell, & Evans, 2013 UK	***Elaborate*** **Forward translation**: 5 deaf people who were bilingual in BSL & Englis. Main author (Rogers) & one of the creators of MH instruments met with the translation team to clarify meanings & produce the 2nd draft **Backward translation:** 2 individuals not previously involved in the study alongside 5 BSL users being invited to complete the measures	Hosting measures online helps to reach a heavily dispersed population	The instructions of CORE-OM refer to "statements" –this made no sense as respondents were not reading statements but watching a signer for each item Frequency anchors were changed e.g. "not at all" to "NEVER" owing to modality – each sign was visually distinct (digitally) Use of the pronoun "I" could be misleading in that respondents may interpret this as what the signer is feeling Anxiety in English can encompass a range of symptoms/feelings but different signs in BSL under different contexts The intensity of facial expressions made clarifying the exact sentence difficult e.g. "I have felt OK about myself" Visually motivated signs difficult to clarify – e.g. "physical violence" - showing punching could lead the participant to think of specifics rather than physical violence more generally Specific signs only work in specific contexts. For example, "WRONG" can indicate "fault", so in the item "I have felt able to cope when things go wrong", "WRONG" was not appropriate Confirmation/negation in BSL difficult as BSL does not follow "Subject, Verb, Object" observed in written English – BSL uses multiple and simultaneous channels Not all English words can be directly translated into BSL, often referred to	Statement of "OVER THE PAST WEEK" was included at the start of each BSL video as more difficult to present owing to video format rather than written, where participant can refer back to this statement constantly	Some items are not culturally appropriate for the deaf community e.g. "Talking to people has felt too much for me" – if perceived as concerning spoken English, a deaf person may strongly agree but alternatively, strongly disagree if perceived as communication via sign Sign language communities are small – it is possible that the signer on the video is known to those who complete the outcome measures. The notion of whether this person is an "insider" or "outsider" may impact on results.

				as "false friends" e.g. warmth, which when translated into BSL, would allude to physical heat Abstract English, such as the use of the word "it" – this was omitted in some items		
24	Rogers et al., 2014 UK	***Elaborate*** **Forward translation:** All members of the deaf community; 3 woman, 2 men and included one deaf qualified BSL/English interpreter, 1 deaf clinical psychologist, 1 deaf mental health support worker and 2 lay deaf people **Backward translation:** 2 deaf individuals (not previously involved) **"Work-through":** 5 BSL users (not previously involved)	Internet hosting allows for greater uptake, as the deaf community is dispersed across the UK	Not reported	Not reported	Not reported
25	Rogers et al., 2016 UK	***Forward-backward only*** **Forward translation:** Two native deaf BSL users who were experienced translators & fluent in written English **Backward translation:** Two registered interpreters (one deaf & one hearing) who were	Emphasize more strongly that a question is asking about the severity of a problem for today only Use of online platform allows reach to highly dispersed deaf community	Not reported	Difficulty in repetition of level descriptors – written language allows comparison e.g. "slight", whereas modality means that this is a different task	A few deaf people explained that "MOBILITY" to them encompassed use of public transport rather than physical ability
26	Rogers et al., 2018 UK	***Forward-backward only*** **Forward translation:** 2 deaf native BSL users who were bilingually fluent & both registered interpreters **Backward translation:** 2 bilingually fluent deaf people (not previously involved)	Not reported in this paper – references Rogers, Young, Lovell, & Evans (2013)	Not reported in this paper – references Rogers, Young, Lovell, & Evans (2013)	Not reported in this paper – references Rogers, Young, Lovell, & Evans (2013)	Not reported in this paper – references Rogers, Young, Lovell, & Evans (2013)
27	Samady 2008 USA	***Elaborate*** **Forward translation:** 3 native signers, 2 interpreters **Backward translation:** 5 additional members: 2 native signers, 3 interpreters **Focus group:** 7 women, 3 men who all had: (a) use of ASL (b) identification with the deaf world (c) participation in the deaf	Signer in videos should remove colloquialisms from sign, wear dark clothing and stand against a solid background 10 second interval between questions allows respondents to answer without stopping/restarting after each item Focus group facilitates diversity	Difficulty translating "accident" as sign derived from "WRONG" – "NO CONTROL" used instead No sign for "meant to be" – idiom for "TRUE BUSINESS" used Difficulty signing "God" as this has different signs for different religions	Not reported	Method requires highly proficient bilingual people from deaf community with above- average degree and education – which may not be representative of

		community (d) shared experiences from having a hearing loss				the deaf community at large
28	Smith & Samar 2016 USA	***Forward-backward only*** **Forward translation:** 5 bilingual ASL/English experts and community members to translate by consensus **Backward translation:** 3 independent bilingual community members	Extensive pretesting of all written measures to improve face validity Vary signers by age, race and gender to provide diverse choice of signers	Not reported	Not reported	Deaf people prefer to share information through dialogic interactions – novel approaches may be considered in future
29	Tweney & Hoemann 1973	***Forward-backward only*** **Forward & backward translation:** Deaf adult Ss – 4 same-sex pairs of similar age (none had acquired ASL as a primary language from their parents) Each S in each pair was required to both forward & backward translate **Production of ASL gloss:** Hoemann (second author)	Sentences were purposely selected to be as difficult as possible, with a range of inflectional endings	If translators limit their coding, it could lead to biased translations e.g. limiting to English sentence structure	Some errors were made in translation owing to missing elements on the videotape, however, this was attributed to equipment malfunction	Not reported
30	Wahlqvist et al., 2016 Sweden	***Forward-backward only*** Professional SSL interpreter skilled in interpreting for persons with deafblindness Research team & interpreter discussed translations	Member of research team known to many respondents, contributing toward high response rate	Not reported	Not reported	Not reported

Table 3

Key linguistic, procedural and cultural recommendations

	Challenge(s)	Recommendations
Linguistic	The linguistic structures of certain questionnaires can prove more difficult than others.	• Consider adapting a simpler, psychometrically sound version of the questionnaire. • Take into consideration the readability scores of the text version in addition to the reliability of test scores and the validity of test scores interpretations.
	Attempting to equate a word or phrase from its written format into sign language.	• Develop a clear strategy on how to address the translation of words/collocations that could prove problematic prior to efforts beginning. • Consult with members of the deaf community in order to identify an equivalent and inclusive term. • Consider a periphrastic term. • Do not be restricted by the literal meaning of the original text. Instead, try to establish the 19 different types of equivalence between original and target language (cf. Herdman, Fox-Rushby, & Badia, 1997; Montoya et al., 2004).
	The structure, content and grammar used in questionnaires is different to that of prose text. The use of pronouns in psychometrics poses a unique challenge to translation efforts.	• Ensure that the pronouns are translated appropriately. • Consider including "YOU WHAT?" at the end of each item to communicate that the statement is a question directed to the responder of the questionnaire.
	Prefacing instructions and response anchors. Retaining the response options in memory whilst responding to each item constitutes a cognitively demanding task which could potentially compromise the respondents' ability to complete the measure accurately.	• Ensure that elements of each item, such as time scales, frames and instructions are reinforced throughout the testing phase. • Ensure that items converted into videos have "replay" function so that the respondent can watch the item again, if needed.
	The linguistic heterogeneity of the deaf population is so large that developing a self-report measure for all deaf people who share the same sign language is not possible due to, for instance, the idiosyncratic developmental pathways of deaf people learning sign language or the use of dialects.	• One size does not fit all. • Be specific of the target population in terms of general ability and sign language fluency. • Use a corpus-based approach based on frequency data for choosing certain sign words. • During the prototyping phase, consider comparing responses of people completing the questionnaire alone vs those who do so with a trained facilitator. • Deaf people with significant language problems might be best served by clinical interviews instead of a self-report measure.

Procedural	Different technologies pose different barriers due to technology specific technical errors and malfunctions or limitations related to changing modality.	• Use internet-based services to host the translated questionnaires. • Develop strategies to account for the digital divide in the deaf population.
	Poor quality videos.	• Strive for good lighting, high quality video capture, an unobstructed view of the signer's facial expressions/signs. • Film against a background with a solid color.
	Pre-empty potential pitfalls that result from the methodological approach to adaptation	• Opt for an elaborate approach to adaptation (and not just a forward-backward approach) in line with relevant translation/adaptation guidelines and the Standards for Educational and Psychological Testing (2014).
Cultural	Identifying the individual(s) who features in the signed version of the measure.	• Consider the pros and cons of employing a well-known signer and the impact this could have on responses. • Consider alternative signers to account for diversity (linguistic and otherwise – e.g. gender, ethnicity, etc.). • Make decisions in consultation with representatives from the deaf community.
	The adaptation of items that do not directly apply to the deaf population (e.g., words such as "hearing" and "talking").	• Contact the original author of the measure for advice and clarification on certain items. • Consider developing the measure in both sign language and text (through close deaf-friendly captions, for example). Be mindful that the captions do not represent the original version of the measure but capture what the signer communicates in the video. • Conduct a pilot testing with feedback on the near final draft of the measure. • Employ cognitive interviews to refine the end product, in line with the Standards for Educational and Psychological Testing (2014).
	The inequalities that many deaf people have historically experienced have often hindered the prospect of reaching their full potential leading to limited spoken language skills (cf. language deprivation) and experience with surveys.	• Be mindful of the wider context within which deaf people navigate the hearing world and how this could invalidate the results. • Consider the cultural nuances of both languages (original and target). • Invest in capacity building of specific deaf individuals to develop the expertise required to support translation/adaption efforts. • Develop and foster a work ethos that is routed on mutual respect and aims to develop the capacity for a shared cross-cultural and interdisciplinary expertise.

Figure 1.

Systematic review PRISMA flowchart screening process. Adapted from Liberati et al. (2009)